

Genomics research and involving the public (GRIP)

Background

In order to meet the NHMRC's call for increased involvement of the public in the research cycle (from prioritisation to implementation), we need a better understanding about ethical and effective ways of involving all people affected by genetic variations of known significance in shaping the future of human genomics research.

For example, the research priorities of people affected by cystic fibrosis (CF) are naturally fragmented by the multiple genetic causes of the disease, creating ethical and practical issues, particularly for involvement in research prioritisation.

It is likely that people affected by many other diseases will begin to be more fragmented in these ways.

Objective

To explore the attitudes and experiences of people affected by genetic variations of known significance towards involvement in genomics research.

Methods

I will undertake a mixed methods thesis. Following ethics approval and a literature review, I will conduct:

- Surveys - assessing knowledge of and attitudes towards genomics research
- Interviews – to explore different perspectives on genomics research
- Focus group discussions – exploring people's experiences of and attitudes towards involvement in research.

Table: Summary of participant groups, methods and analytical approach

Participant groups	Involved in shaping research design	Data collection methods			Analysis
		Surveys	Interviews	Group discussions (online or in person)	
General public	✓	✓	✓	✓	Quantitative and qualitative methods, integrated in a synthesis of overall findings
People affected by genetic variations of known significance, including people affected by CF	✓	✓	✓	✓	
Clinicians (including those using genetic testing)	✓		✓		
Genetic counsellors and researchers	✓		✓		
Subject experts (e.g. ethicists, lawyers)	✓		✓		
Policy makers	✓		✓		

Dissemination and translation

I will prepare a thesis by publication. In addition I will share recommendations to inform:

- Government policies, research active organisations, patient and consumer organisations.
- The creation of a validated method to enable ethical and facilitated conversations between people with genetic variations of known significance (i.e. peer-to-peer) and researchers.

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